

**Children's Special Health Services  
Family Advisory Council Meeting Minutes  
August 20, 2005**

Present from the Family Advisory Council: Lisa Beckman, Carla Peltier, Lori Hanson, Jennifer Restemayer, and Cheryl Klee.

Present from CSHS: Sue Burns, Leann Bayman and Tammy Gallup-Millner.

Present from the Health Department: Kim Senn.

**CSHS Updates:**

- Follow-up from May meeting – Minutes were accepted as written. The council was informed that efforts were underway to reclassify Terry's old position and that a new person would likely be hired in the next couple of months. The Health Department recently found out they will be able to hire an epidemiologist as well. These two positions should complement one another. The draft work plan developed by CSHS staff in follow-up to the annual Medical Advisory Committee meeting was reviewed. Family Advisory Council members indicated the \$20,000 worth of care through CSHS is helpful and agreed with the addition of muscular dystrophy and coverage of formula supplements on a case-by-case basis. The group was informed that conditions are occasionally added but rarely dropped from the list. Tammy relayed the work plan will be reviewed within DHS before any changes are initiated by CSHS. No comments were received about the updated review/recommendation form.
- CSHS programmatic reports –
  - New care coordination form – Tammy relayed that advice from the council was reviewed when finalizing the form. It will begin to be used effective October 1, 2005. County staff will receive training on use of the form in October. Family Advisory Council members relayed the new form was less intimidating, had a nice resource section, and that they liked the reference to the care notebook, which includes an emergency form for CSHCN.
  - Public information update – Tammy relayed that staff have been busy with a variety of public information activities including: 1) hard copy and electronic dissemination of the CSHS library catalog, 2) planning for county training 10/25/2005-10/26/2005, 3) July radio show on children with disabilities, 4) planning for August SSI meeting, 5) planning for September clinic coordinator meeting, and 6) June site visits to county staff and contract providers. Advisory council members recommended the library catalog be available on the website and sent to public health, school nurses, childcare resource and referral staff, early intervention staff, and Head Start staff.
  - First Sounds update – Sue relayed that Minot State University received two new grants. The HRSA grant will continue to address hospital screening while the CDC grant, known as project Kaylyn, will address follow-up after the baby leaves the hospital. Issues being addressed lately include: hospital data agreements, upcoming health summit, collaboration with Part C (early intervention), hospital site visits, authorization for hearing screening, and screening at the two week check-up rather than before hospital discharge.

- Champions for Progress update – Tammy relayed that ND had submitted a proposal for an incentive award but was not funded due to federal budget cuts; however, a four-person team still plans to attend a planning meeting in Utah in September.
- Title V Block Grant application review – Tammy relayed the block grant application was available if anyone wants a copy. The August review overall was positive and focused heavily on the five year needs assessment. The results of the family involvement measure that combined CSHS staff and Family Advisory Council rankings was shared. Overall, ND ranked 16 out of 18 (89%). This ranking will likely not increase unless CSHS hires a family member as a paid staff member or contracts for the services of a family consultant. Council members indicated that more work is needed regarding family-centered care in the private health care system based on recent visits to the University of Minnesota and Shriners Hospital.
- Service contracts awarded for the 2005-2007 biennium – Tammy relayed that similar contracts were funded this biennium as last biennium. BECEP did not submit an application this year and the asthma clinic grantee changed from Mid Dakota Foundation to St. Alexius.
- Medical Needs Task Force – Jennifer relayed at previous meetings, the group focused on definition and number of CSHCN's in the state. Tammy relayed she and Deb Balsdon were now co-leading the group and that a meeting was scheduled for September 12, 2005 from 10:00 – 3:00 in Bismarck. The membership is being expanded to include more “health” representatives in addition to those from the disability community.
- Budget Committee on Human Services – This interim committee met in Bismarck on July 28, 2005. Section 3 of SB 2395 requires DHS to apply for a Medicaid waiver to provide in-home services to children with extraordinary medical needs who would otherwise require hospitalization or nursing facility care. The committee appeared supportive about having the input of the Medical Needs Task Force as planning efforts for the waiver get underway. HCR 3054 was selected as an interim legislative study that will determine whether there are unmet health needs and gaps in the state's system for providing services to CSHSN, which should be addressed. Discussion during the committee meeting initially focused only on Children's Special Health Services. It is not yet clear whether the Legislature will take a broad systems approach to address these complex issues or a less comprehensive programmatic approach. The next meeting for the Budget Committee on Human Services is tentatively scheduled for September 28, 2005.
- Department of Health update – Kim Senn provided an update and handouts on Healthy North Dakota (HND). Families can contact Melissa Olson if they are interested in more information. Currently, there are 400 members in HND throughout the state. During the past session, the Health Department was able to educate the legislature on preventive health and strengthen collaborative partnerships of state and community leaders. Kim also relayed that school health guidelines, which include a section on CSHCN's, will be completed by January 2006. Carla indicated the guidelines would be helpful to teachers. Dakota Medical Foundation has provided funding for a model school nurse program. In terms of evaluation, initial findings indicate that a higher percentage of kids are able to stay in school rather than be sent home by a teacher or secretary if a school nurse is present. Stakeholders are currently strategizing about funding for school nurse programs. Lori indicated that nurses are no longer certified as school nurses through the ANCC. The Newborn Screening

Advisory Council has recommended that screening for cystic fibrosis be added. This will likely start January 2006 after administrative rules have been changed. Out of the 20-30 with positive screens, eight babies are expected to be identified with the disease. Clinics are available for follow-up in Bismarck and Fargo. The early childhood comprehensive systems grant has an advisory group, which is working on a state plan. Subcommittees have been formed to work on action steps. One of the subcommittees focuses on medical home and access to insurance,. Family support is integrated into all of the organized subcommittees.

**Guest Presenter:**

Jodi Hulm, a community Resource Coordinator (CRC) from the Linton Hospital provided information and handouts regarding the CRC network and how coordinators promote access to healthcare. Her position started September 2001. Thirteen positions were initially funded in the western half of the state through a Northland Community Alliance Grant, nine of which have been sustained by local health care facilities. Dakota Medical Foundation has since funded CRC positions in the eastern half of the state. CRC's help people of all ages enroll in a variety of health care programs and provide education on other assistance that might be available (e.g.) Food Stamps, childcare, prescription assistance, etc. Hospitals let local CRC's know if a family is uninsured. Enrollment in available programs helps reduce "community care" that facilities typically would write off. A few gap communities remain in the state (e.g.) Wishek, tribal communities such as Fort Yates and Newtown, Dickinson, etc.

**New Definition of Family-Centered Care and Cultural/Linguistic Competence:**

Members reviewed the new definitions and principles being promoted by the Maternal and Child Health Bureau. Council members recommended they be used to create awareness and educate the public especially on cultural impacts and the need to respect the skills and expertise families have acquired as the primary caregivers for their children.

**Next Meeting:**

The next meeting will be held Saturday, November 19, 2005 from 9:00 – 12:00 noon.